

**The Under-Representation of Women Living with Disabilities in the Literature on
Sexual Health**

Caryn Lafreniere
Capstone

Abstract

Using a critical literature review (with an emphasis on the Canadian context) I illustrate that the literature on the sexual health of women living with disabilities is sparse, fragmented and rarely addresses intersecting forms of oppression. Using the literature, I argue that the exclusion of women living with disabilities from the sexual health literature is itself a systemic health inequity. Additionally, I argue for the use of intersectionality as a framework for research that can best capture the complexities of women's experiences of disability and sexual health.

Contents

Abstract	1
Introduction: Disability and Gender as a Public Health Problem	4
Framework	7
Positionality	9
Methods	13
Type of Literature Review	13
Search Methods	13
Resource Analysis (i.e. Inclusion/ Exclusion Criteria).....	15
Framework	17
Critical review of relevant literature / Results.....	18
Imbalance in the Research.....	18
Lack of Research	19
Second- Hand Accounts of Disability	20
Invisibility and Oppression of Women Living with Disabilities	21
Lack of Sexual Health Education, Information, Resources, Supports and Programs.....	23
Articles on Men Living with Disabilities	26
Abuse of Women Living with Disabilities.....	29
Exclusion from Sexual Health Arena as Abuse.....	31
Intersections of Sexism and Disability	33
Recommendations	42
Research:.....	42
Information and “Self-Responsibility”:	43
Increased Representation in Sexual Health Services and Programs:.....	44
Funding and Policy:	45
Discussion.....	47

Summary of Critical Review	47
Limitations	47
Implications for public health practice and/ or policy	48
Disability and Intersectionality Theory	49
Recommendations	50
Intersecting Categories	50
Multi-Level Analysis	52
Diverse Knowledge's'	53
Conclusion.....	54
References	55
Appendix A.....	60
Appendix B.....	62

Introduction: Disability and Gender as a Public Health Problem

Women living with disabilities in Canada face undue marginalization, especially when it comes to their sexual health (Riddell et al, 2003; Masuda, nd; Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011). In Canada, women living with disabilities are more likely to live in poverty, face unemployment, be marginalized and isolated, and experience high levels of sexual violence and abuse (Masuda, nd; Yoshida et al, 2011). Women living with disabilities have historically been oppressed, and continue to face high levels of oppression; they face a double burden of marginalization as a result of sexism and ableism. This plays out in regards to their sexuality through erroneous stereotypes of women living with disabilities as “oversexed”, and paradoxically, at the same time, “asexual” or “childlike” (Tutty et al, 2010a; Foster & Sandel, 2010; Yoshida et al, 2011). These stereotypes result in sexual health inequities such as exclusion from sexual health education, information, and research (Tutty et al, 2010a; Tutty et al, 2010b); reduced access to reproductive services (such as screening and family planning)(Riddell et al, 2003), and increased risk of negative consequences (such as STIs and unwanted pregnancies) (Long et al, 2011); higher rates of sexual violence and abuse (Foster & Sandel, 2010; Yoshida et al, 2011); and internalized oppression resulting in low sexual self-confidence and worth, and negative perceptions of sex (Bernert & Ogletree, 2013). I will argue using an Intersectional Theory framework via a critical review of the literature that the lack of research concerning the sexuality of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011), as well as the lack of programs, resources, supports, and information (Dotson et al, 2003; Foster & Sandel, 2010; Long et al, 2011; Jeffreys, 2008; Masuda, nd; Riddell et al, 2003; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Yoshida et al, 2011), and the exclusion from sex education (Richards et al, 2008; Shandra & Chowdhury, 2012; Tutty et al, 2010a, Yoshida et al, 2011), is itself a systemic health inequity. Namely, that this

exclusion from the sexual health arena is representative of a systemic inequity as it concerns the sexual health of women living with disabilities.

The population under discussion in this critical literature review is women living with disabilities, with a specific focus on the Canadian context. Thus, this paper aims to look at how the exclusion from sexual health support, education and research impacts all women living with disabilities in Canada (Tutty et al, 2010a). Unfortunately, while a broader focus might help in gaining a better picture of how the sexual health of women living with disabilities is treated as a whole, it also can lead to generalizations. Women living with disabilities are not a “social monolith” (Foster & Sandel, 2010 p.180). While this paper aims to examine all women living with disabilities regardless of disability or disability type, or of time of onset, or other social locations, this does not mean that all women living with disabilities are the same or have the same experiences. While getting an idea of how patterns or systemic inequities are operating is very important, and is the main rationale behind why I am looking at this population as a whole, this does not mean that I view this population, women living with disabilities, as interchangeable or as a monolith. This population includes a range of disabilities, different women, and social locations, which will inevitably lead to different experiences. For example, disability is something which can occur across the lifespan and something like time of onset of disability will have a great impact on that woman’s experience of her disability. This is similar to other factors, such as if a woman lives in poverty, is a woman of colour, or has experienced abuse. Notably, the reason I am calling for the use of intersectionality theory in this type of research is because I realize that a theory which best deals with complexities and multiple social locations is best suited to examine an issue as complex as this, with a population that is not monolithic and has divergent intersecting experiences (Foster & Sandel, 2010).

Foster & Sandel (2010) argue that women living with disabilities have historically been oppressed, and continue to face high levels of oppression today. Yet, this oppression is often hidden from view and, similar to other groups facing undue marginalization, the oppression, and in fact women living with

disabilities themselves, become hidden from view or “invisible”. Because women living with disabilities are seen as not conforming to hegemonic discourses of able-bodiedness, heteronormativity or femininity, they are hidden from view and are thus “invisible”. This invisibility extends to the oppression they face as a result of not conforming to sexist and ableist standards (Foster & Sandel, 2010). The enactment of this invisibility as a mechanism becomes more apparent when we shed light on the exclusion of women living with disabilities from sexual health research, programs, policy, and services (Dotson et al, 2003; Wells, Clark & Sarno, 2012). This exclusion, this lack of representation, in a group that faces ableism and sexism and the resulting consequences of those forms of oppression, is a huge issue (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Bumiller, 2008; Wells et al, 2012; Zitzelsberger, 2005; Long et al, 2011; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Sanders, 2007; Jeffreys, 2008). Representation really matters, and it can have huge consequences (Dotson et al, 2003; Wells et al, 2012); furthermore, the fact that this group has historically experienced and currently experiences sexual health inequities due to sexist and ableist stereotypes surrounding women living with disabilities as asexual or oversexed (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Zitzelsberger, 2005; Tutty et al, 2010a; Tutty et al, 2010b; Richards et al, 2008), points to the idea that this exclusion is the root of a larger problem, and thus is in fact a systemic health inequity.

Framework

The main theoretical approach I will be using to analyze the literature review is that of intersectionality theory; mainly because an intersectional approach is needed to best delve into the complexity of this health inequity since it exists at the intersection of at least two forms of marginalization: sexism and ableism (Foster & Sandel, 2010). Intersectionality (as a concept and theory) was coined by Kimberle Crenshaw in her ground-breaking essay "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics" (1989). Crenshaw, a black feminist, was critiquing the exclusion of black women or women of colour from feminist theory and critical race theory and as a response created the concept of "intersectionality" (Crenshaw, 1989). Intersectionality posits that in order to fully understand inequity we must examine how different axes of oppression and privilege intersect. It is not an additive or multiplicative model but rather examines how these intersections, where various forms of marginalization and/or privilege meet, are enacted by the people who experience them (Hankivsky & Christoffersen, 2008). Intersectional frameworks allow us to look at the intersections of multiple axes of oppression and privilege, to see how these axes intersect and how these intersections can sometimes cause compounded sites of privilege or oppression. The guiding principles pay explicit attention to: intersecting categories, multi-level analysis, power, reflexivity, time and space, diverse knowledge's, social justice, and equity (Hankivsky et al, 2012). Intersectionality theory is appropriate for this issue since as mentioned above, women living with disabilities face multiple forms of oppression: sexism and ableism compound to create a unique site of oppression, and thus, intersectionality theory is an appropriate choice since it is uniquely suited to analyzing said sites of oppression (Foster & Sandel, 2010)

An analysis informed by intersectionality theory is also useful when there is a lack of research on the subject. Multiple authors¹ mention the benefit of using intersectionality as a way of making connections in diverse and complicated subject matters (Moodley & Graham, 2015; Pal, 2011; Shaw, Chen & McMahon, 2012). Intersectionality theory allows one to make connections across disciplines even if the research is fragmented and sparse. For instance, since I was looking at how gender and disability interact to affect the sexual health of women living with disabilities, I was able to pull out themes in the literature which reflected this interaction. I was also able to notice the intersection of disability and sexism across the literature by specifically looking for evidence of these interactions in various sources. Thus, employing an intersectional lens which kept in mind the interactions of disability and gender and how this affects the sexual health of women living with disabilities, allowed me to more cohesively analyze the literature.

Although I attempted to use an intersectional lens while conducting a critical review of the literature, the main way I will employ intersectionality theory in this paper is through a Disability and Intersectionality Theory section, and my Recommendation and Positionality section. In the Disability and Intersectionality Theory section, I will provide further justification of why intersectionality theory is important in disability studies using articles that promote using this theory in disability studies. And in my Recommendation section I will use various guiding principles of intersectionality theory to guide my recommendations: intersecting categories, multi-level analysis, and diverse knowledge's'. I am also employing the guiding principle of "reflexivity" by including a Positionality section in this paper, in order to socially locate myself within the issue.

¹ These are articles found outside of the critical literature review. They are articles I looked for specifically to find research on the benefits of using intersectionality theory when it comes to disability.

Positionality

As mentioned above, one of the core tenets of intersectionality theory is reflexivity. Reflexivity points out the importance of being as aware as possible of how your lived experiences and relative position of privilege/and or marginalization affect how you view an issue. What I mean by this is “what knowledge, values, and experiences do you bring to this area of analysis” (Hankivsky et al, 2012, p. 39). This is important because your social location often affects how you perceive an issue, for instance in general, if you self-identify as a woman this may affect how you view sexism. Your social location also determines which resources you have access to, how you are able to navigate society, and often how you are treated. This is not to say that one’s life is determined by one’s social location but it is definitely affected by it and often influences your position on an issue (Hankivsky et al, 2012). Therefore, to be as upfront as possible and in order to uphold the ideals of intersectionality theory, I will attempt to position myself within the issue at hand: the exclusion of women living with disabilities from the sexual health arena. This is extremely hard for me to do since I personally identify with and have had experiences related to the issue (i.e. I am a woman living with a disability). Thus, while attempting to use positionality, I often become too personal and fail to actually perceive how my positionality may also affect me systemically. I think it is also extremely hard on a personal level to be aware of how marginalization may play out in your life. Sometimes there are very clear incidents of prejudice which you can point to, but when we talk about societal or systemic exclusion, that is something which is often very hard to pinpoint. This is similar to when discrimination plays out in subtle yet pervasive ways. As well, while conducting this literature review, I became very upset and depressed by many of the statistics surrounding women living with disabilities in Canada. They experience such high rates of marginalization; as a woman living with a disability in Canada, I don’t want to be one of those numbers. Even though in some cases I know that sometimes my experiences will align with a certain statistic, for example, women living with disabilities in Canada will face higher rates of unemployment than

women without disabilities or men living with disabilities (Shandra & Chowdhury, 2012). Although I am working part-time now (not in my field) which is also more common for women living with disabilities according to the statistics (Shandra & Chowdhury, 2012), I remember this little nugget was quite the bummer during a long period of fruitless job searching. Moreover, perhaps due to the fact that I have internalized negative stereotypes about women living with disabilities, since my disability is to all intents and purposes “hidden”, I wondered if my inability to find a job in my field was due to me rather than my disability. Which I suppose helps illustrate the fact that sometimes it is very hard to see how marginalization actually affects your life especially in a culture based on meritocracy, where it is encouraged to assume any of your perceived societal failings are in fact due to something you lack (especially if you are part of a minority in any way), rather than the fact that the system is inherently unfair and biased.

In terms of Positionality, I identify as a white, cis-gender, heterosexual female in her late twenties. I am currently finishing my Masters of Public Health, which reflects a certain level of privilege. I was raised by a single mom; however, my mother had a good job and thus my experiences have been buffered by the fact that I also hold class privilege (as well as white and cis privilege). Perhaps, most relevant to this issue (as mentioned before), I am also a woman living with a disability, and I have the unique experience of my disability being both visible and invisible. I was born with a very rare condition which affects the retina, and is thus not corrective. When I was younger and my disability was worse and thus “visible”, like many kids living with disabilities, I experienced teasing, discrimination, and exclusion from my peers (Klett & Turan, 2012; Shandra & Chowdhury, 2012). Additionally, my relationship with my father was very influenced by the fact that I had a disability, which as Shandra & Chowdhury (2012) argue is common for girls living with disabilities. He was very uncomfortable with it, to the point that when my disability became “hidden” (i.e. my eyesight had improved and I became very well adapted to the point where no one or very few people could tell I had a visual disability); he staunchly denied that I in fact had one. Having an invisible disability, comes with the privilege of being able to hide your disability, and thus escape stigma in many ways; however, it

does come with the pitfall of constantly having to prove or justify the fact that you do in fact still have a disability which continues to affect your life. I unfortunately, had a similar experience with a past partner who I lived with for two years, who also refused to acknowledge the fact that I had a disability or that it could affect me in any way. Sadly this is a common experience for women living with hidden disabilities. As Tutty et al (2010b) state “For some of the women, the invisibility of their condition resulted in being denied help, support, and understanding” (p.44).

I also, like many women living with disabilities in Canada, have experienced abuse (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al 2010b). While I was lucky enough to never receive physical abuse, both my relationship with my father and my past partner were at the very least emotionally abusive. Furthermore, after exiting this unhealthy relationship, I noticed that my self-worth was at an all-time low, and that my sense of sexuality was also very impacted by these experiences. This is not surprising since women living with disabilities, as a result of their experiences of sexism and ableism and from an internalization of the stereotypes surrounding these discourses, are known to have low self-worth and a low sense of sexual self-esteem (Shandra & Chowdhury, 2012; Tutty et al, 2010a; Jeffreys, 2008; Zitzelsberger, 2005). Nonetheless, during this vulnerable period in my life where my sense of sexuality had been impacted, I actively looked for resources and support to help regain a healthy sense of sexuality. I was not able to find anything. While I wasn't specifically looking for resources geared towards women living with a disability and their sexuality, I did notice the fact that this group (and I) were not represented when it came to sexuality at all. Perhaps it is not surprising then that the main argument of this critical literature review became that the lack of sexual health resources, information, and research for women living with disabilities in Canada is a systemic health inequity (Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Franco et al, 2012; Long et al, 2011).

My social location also no doubt influenced my research and analysis of this critical literature review. I honestly think that in some ways it may have influenced it for the better, since I believe that by having experiential knowledge you often already have an understanding of the issues on a very visceral level. It actually reminds me of the guiding principle of “diverse knowledge” in intersectionality theory (Hankivsky et al, 2012). I feel like there is something intrinsically useful when you bring experiential knowledge to the table. However, in some ways it is possible that it biased how I analyzed the issue. For instance, since I have a “hidden” disability, I may have put been more drawn to mentions of it in the literature than I would have otherwise. Furthermore, it may also have impacted my analysis; sometimes when you have this gut understanding of an issue, you don’t always clearly describe it. What I mean by this is that in some cases you take for granted that others see what you see, and thus you don’t need to explain or prove it. In this way, it may have affected my analysis.

Also going back to the guiding principle of “diverse knowledge” in intersectionality theory, the fact that I, a woman living with a disability, am the one doing the research (or more specifically analyzing it) holds benefit (Hankivsky et al, 2012). Women living with disabilities are largely not in charge of the research being conducted about them; instead research on the sexual health of women living with disabilities is often done via second-hand accounts, or done by people living without disabilities (Dotson et al, 2003). This is of course reflective of the sexist ableist power imbalance existing currently in this field of research, namely where the voices of women living with disabilities are excluded from research, even when it is about their sexual health, and often those with more power (whether it be from white privilege, male privilege, able body privilege, etc.) are in charge of conducting and analyzing the research (Dotson et al, 2003).

Methods

Type of Literature Review

Grant & Booth (2009) identify 14 types of literature reviews: critical, literature, mapping, meta-analysis, mixed studies/mixed methods, overviews, qualitative systematic reviews, rapid, scoping, state-of-the-art, systematic, systematic search and review, systematized, and umbrella reviews. Using the 14 types of reviews in this article as a template, I identified and chose the critical review as the most appropriate for what I hoped to accomplish in this paper. I felt that the critical review best embodied the needs for this field of research and thus this paper since it “goes beyond mere description to include a degree of analysis”, and since part of the search component of a critical review is to “identify the most significant items in the field” (Grant & Booth, 2009, p.94). The critical review also gives you the leeway to appraise which articles are included in the review by attempting “to evaluate according to contribution” (Ibid). A critical analysis of the themes found in the literature was imperative for me since I am employing an intersectional lens and coming from a social inequities perspective, both of which place high value on a critical lens. Also, since this issue is so complex and multilayered, a critical lens is best suited for this field of research. Furthermore, since there is a dearth of research in this area, I had to use broader search terms to obtain any results and thus needed a higher amount of latitude in determining the relevancy of my sources. Critical reviews also do not have high exclusion criteria (i.e. it doesn't have to be all peer reviewed, or only qualitative studies etc. [Grant & Booth, 2009]), which was helpful since there is a lack of research in general, and thus higher criteria would have worsened this situation.

Search Methods

I searched through 3 databases for this review: *Sociological Abstracts*, the *Cumulative Index of Nursing and Allied Health Literature* or *CINAHL*, and the *Canadian Public Policy Collection*; and through the research on the *BC Centre of Excellence for Women's Health*. These searches yielded a total of 27

(relevant) sources, or to be more precise: 22 articles (Areskaug- Josefsson & Oberg, 2009; Braswell, 2015; Breiding & Armour, 2015; Bernert & Ogletree, 2013; Inahara, 2009; Foster & Sandel, 2010; Dotson, Stinson & Christian, 2003; Fritz, Dillaway & Lysack, 2015; Yoshida, Dumont, Odette & Lysy, 2011; Sanders, 2007; Klett & Turan, 2012; Kehmann, 2005; Liddiard, 2014; Shandra & Chowdhury, 2012; Bumiller, 2008; Wells, Clark & Sarno, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Franco, Cardoso & Neto, 2012; Long, Krowczyk & Kenworthy, 2011; Wearing, Gunaratnam & Gedalof, 2015; Wilson, Parmenter, Stancliffe, Shuttleworth & Parker, 2010), 4 reports (Riddell, Greenberg, Meister & Kornelsen, 2003; Masuda, nd; Tutty et al, 2010a; Tutty et al, 2010b), and 1 book chapter (Richards et al, 2008). As a result of including the *Canadian Public Policy Collection or CPPC* as a database for the literature review and a report from the *BC Centre of Excellence for Women’s Health*, the findings were a mix of academic and grey literature, which included articles, reports and chapters. While all the sources found through *Sociological Abstracts* and *CINAHL* are academic, those found through the *CPPC* and the *BC Centre of Excellence for Women’s Health* would most likely be considered “grey” literature. However, due to the dearth of research it seemed unwise to be limited to only peer-reviewed articles. In fact, the source from the *BC Centre of Excellence for Women’s Health* was found via word of mouth, since a peer recommended the report as a source of information on the sexual health of women living with disabilities with a specifically Canadian context. Moreover, many of the sources specifically analyzing the Canadian context for women living with disabilities were “grey” literature, and thus were included since I wanted this paper to reflect the Canadian situation for women living with disabilities as much as I possibly could.

<u>Type of Source</u>	<u>#</u>	<u>Peer- Reviewed</u>	<u>Grey Literature</u>
Article	22	Yes	No
Report	4	No	Yes
Book Chapter	1	No	Yes

<u>Total:</u>	27	22	5
---------------	----	----	---

The sources found in this critical literature review are also a range of different types of research which I have split into two groups: original research, and reports, analyses, reviews, and perspectives. There were 17 original research studies: Wilson et al, 2010; Breiding & Armour, 2015 Yoshida et al, 2011; Tutty et al, 2010a; Masuda, nd; Riddell et al, 2003; Dotson et al, 2003; Klett & Turan, 2012, Shandra & Chowdhury,2012; Tutty et al, 2010b; Wells et al, 2012; Zitzelsberger, 2005; Franco et al, 2012; Long et al, 2011; Bernert & Ogletree, 2013; Liddiard, 2014; Fritz et al, 2015), and 10 reports, analyses, reviews, and perspectives: Braswell, 2015; Lehmann, 2005; Inahara, 2009; Foster & Sandel, 2010; Sanders, 2007; Richards et al, 2008; Bumiller, 2008; Jeffreys, 2008; Areskoug-Josefsson & Oberg, 2009; Wearing et al, 2015 (see Appendix A for table). Both Lehmann (2005) and Braswell (2015) are perspectives. Braswell (2015) talks about his own experience of being given up for care in the context of moms living with disabilities, and Lehmann (2005) talks about her experience as a family planning nurse as it relates to the sexual health of women living with disabilities. However, they are not categorized as original research because while I value experiential knowledge neither article conducted any research, and instead both articles seem to rather be analyses of the issue drawing on personal experiences.

Resource Analysis (i.e. Inclusion/ Exclusion Criteria)

The search conducted through *Sociological Abstracts* utilized the search terms “disability” (AND) “sexuality” (OR) “sexual health’ ” (AND) “women” (OR) “female”, with the limits of “peer-reviewed”, and published after 2003, yielded 43 results, 14 of which were relevant. The *CINAHL* search included the same limits; however, the search terms were “disability” (AND) “sexual health” (AND) “women”. This search garnered 17 results, 8 of which were relevant. For the *Canadian Public Policy Collection (CPPC)* database

search, the terms “sexual health” (AND) “women with disabilities” were used. This led to a total of 91 results, 4 of which were relevant.

<u>Databases</u>	<u>Search Terms</u>	<u>Limits</u>	<u>All Results</u>	<u>Results Included</u>
<i>Sociological Abstracts</i>	“Disability” AND “Sexual Health” OR “Sexuality” AND “Women” OR “Female”	<ul style="list-style-type: none"> • Peer reviewed • Published after ≥ 2003 	43	14
<i>CINAHL</i>	“Disability” AND “Sexual Health” AND “Women”	<ul style="list-style-type: none"> • Peer reviewed • Published after ≥ 2003 	17	8
<i>Canadian Public Policy Collection</i>	“Sexual Health” AND “Women with disabilities”	<ul style="list-style-type: none"> • Published after ≥ 2003 	91	4
<i>BC Centre of Excellence for Women’s Health</i>	None*	None*	1	1*
Total:			152	27

*As mentioned earlier, on the suggestion of a colleague, an additional report was found via a search through the research published by the *BC Centre of Excellence for Women’s Health*, and thus had no limits or search terms for this particular result, making the total of sources found 27.

Since one of the aims of this paper was to provide a Canadian analysis, I used as many Canadian studies and sources as possible although unfortunately the total of Canadian sources included was 8 (see Appendix B for table). This is the main reason I used the Canadian Public Policy Collection as a database choice since, as the name implies, it contains policy documents and reports from a Canadian context. This is also why I chose to include the word of mouth suggestion, i.e. the report from the *BC Centre of Excellence for Women’s Health*. Moreover, to help me generalize to a Canadian context as much as possible, I excluded sources which weren’t from “Western” countries (see Appendix B for a breakdown of source by country). Other exclusion criteria were: for sources without a full text, sources in languages other

than English, and sources deemed “irrelevant”. As mentioned above, although the search terms in the various databases garnered more results than utilized, only 27 results were deemed relevant. I determined relevancy by examining whether or not the article, report, or chapter, actually discussed the sexual health or sexuality of women living with disabilities (and as mentioned previously, the source analyzed the issue from a “western” perspective). In fact, many sources were deemed relevant even if their sole focus was not on the sexuality or sexual health of women living with disabilities (i.e. instead their focus may have been on the sexual health of people living with disabilities or even men living with disabilities², or on the abuse women living with disabilities face, or on health barriers in general for women living with disabilities) as long as some component of the article, report, or chapter provided some perspective or analysis on the sexuality or sexual health of women living with disabilities. As may be evident by my explanation of what constituted relevancy, there was a scarcity of research on this subject.

<u>Exclusion Criteria</u>
Full text not included
Published in a “non-Western” country OR examining the context of disability issues in a “non-Western” country
Source in another language than English
Deemed “irrelevant” (i.e. see explanation above)

Framework

As mentioned earlier, the main framework I will be employing will be intersectionality theory. The main way I will be using intersectionality theory is through my Positionality section and Recommendation section, and through a Disability and Intersectionality Theory section.

² Articles on men living with disabilities were included if they provided some sort of gender analysis of the role of disability and sexuality as it relates to women living with disabilities.

Critical review of relevant literature / Results

Imbalance in the Research

The articles found by searching through *Sociological Abstracts*, *CINAHL*, the *Canadian Public Policy Collection*, and the *BC Centre of Excellence for Women's Health* yielded a total of 27 sources (Areskaug- Josefsson & Oberg, 2009; Braswell, 2015; Breiding & Armour, 2015; Bernert & Ogletree, 2013; Inahara, 2009; Foster & Sandel, 2010; Dotson, Stinson & Christian, 2003; Fritz, Dillaway & Lysack, 2015; Yoshida, Dumont, Odette & Lysy, 2011; Sanders, 2007; Klett & Turan, 2012; Kehmann, 2005; Liddiard, 2014; Shandra & Chowdhury, 2012; Bumiller, 2008; Wells, Clark & Sarno, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Franco, Cardoso & Neto, 2012; Long, Krowczyk & Kenworthy, 2011; Wearing, Gunaratnam & Gedalof, 2015; Wilson, Parmenter, Stancliffe, Shuttleworth & Parker, 2010; Riddell, Greenberg, Meister & Kornelsen, 2003; Masuda, nd; Tutty et al, 2010a; Tutty et al, 2010b; Richards et al, 2008). These sources represent an array of viewpoints and subject matters; that is to say, while all the articles deal with the sexual health of women living with disabilities in some manner, many of them approach it from different angles. Although many of the articles focused on disabilities in general (Foster & Sandel, 2010; Liddiard, 2014; Wearing, Gunaratnam & Gedalof, 2015; Breiding & Armour, 2015; Riddell et al, 2003; Masuda, nd; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Sanders, 2007; Jeffreys, 2008; Wilson et al, 2010), some articles focused on specific forms of disabilities. For instance, many of the articles centered on developmental or intellectual disabilities (Bernert & Ogletree, 2013; Lehmann, 2005; Dotson et al, 2003; Richards et al, 2008; Wells et al, 2012; Franco et al, 2012; Long et al, 2011; Klett & Turan, 2012; Bumiller, 2008), and out of those that focused on developmental or intellectual disabilities, a couple specifically looked at Autism Spectrum Disorder (Klett & Turan, 2012; Bumiller, 2008). On the other hand, three of the articles concentrated only on physical disabilities (Inahara, 2009; Yoshida et al, 2011; Zitzelsberger, 2005). This discrepancy, namely the far larger amount of research on the sexuality of people with intellectual disabilities than on those living with physical disabilities, seems to indicate that

there has been more research done on the sexuality of people with developmental disabilities. It is also possible that this imbalance would have been altered, or more articles could have been found, if I had conducted the critical literature review search via disability type or specific disabilities instead of looking for “disability” as a search term in general. However, since there are numerous types of disabilities and I was hoping to gain a broader understanding of the literature around sexual health as whole for women living with disabilities, I used the term “disability” as a catch-all instead of searching by specific disabilities or disability types.

Lack of Research

Nevertheless, even though it seems an imbalance exists on the amount of research available on the sexual health of people with disabilities by form of disability, one thing that most of these sources have in common is the agreement that there is a lack of research on the sexual health of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). Tutty et al (2010 a) state that research is “extremely limited and fragmented; often it does not distinguish either the nature of the disability, gender differences and differences between adults and children” (p. 13). Moreover, Tutty et al (2010a), and Tutty et al (2010b) found that a lot of the research which is out there is old and outdated. Both Tutty et al (2010a) and Tutty et al (2010b) speak to the Canadian context since both are reports done on the situation of people living with disabilities in Canada. Furthermore, in the needs assessment conducted by Tutty et al (2010a) with 20 key individuals doing community work with people living with disabilities in Canada (or more specifically Calgary): lack of research, specifically in the Canadian context, arose as one of the needs which needs to be rectified in order for the community (and community workers) to better serve people living with disabilities in Canada. In addition, Riddell et al (2003)

conducted community action research with women living with disabilities in BC in order to identify barriers to their gynaecological and breast health. And they argued that “In Canada, and specifically in BC, it is difficult to obtain accurate information about the overall demographics of disabilities and women with disabilities” (p.1). This showcases the lack of research around women living with disabilities in Canada. This dearth of research is further compounded when looking for research that touches on the sexuality or sexual health of women living with disabilities since as Dotson et al (2003) maintain “sex remains an uncomfortable topic to directly discuss in both disability and mainstream culture” (p.197)³.

Second- Hand Accounts of Disability

A further critique of the lack of literature surrounding the sexual health of women living with disabilities, is the fact that as Dotson et al (2003) claim “much of the information ‘known’ about the personal beliefs and experiences of women with developmental disabilities, their needs, desires, and sexual practices, have been gleaned from second-hand accounts and speculation” (p.195). Although this quote refers to women living with developmental disabilities, unfortunately, it actually speaks to all women living with disabilities as shown by various other articles (Inahara, 2009; Riddell et al, 2003; Masuda, nd; Zitzelsberger, 2005; Foster & Sandel, 2010). Therefore, not only is there a lack of research on the sexual health of women living with disabilities in general; but this issue is further compounded when it comes to the voices of women living with disabilities themselves. That is to say, for the most part, women living with disabilities’ own views on their sexuality are mostly missing from the literature (Inahara, 2009; Riddell et al, 2003; Masuda, nd; Zitzelsberger, 2005; Foster & Sandel, 2010; Dotson et al, 2003).

³ This lack of research concerning the sexual health of women living with disabilities is a large part of the reason why Dotson et al (2003) felt the need to conduct their own original research looking at the personal perspectives of women living with disabilities on sexuality, sexual health and reproductive rights.

Invisibility and Oppression of Women Living with Disabilities

Foster & Sandel (2010) argue that the lack of research into the sexual health/ sexuality of women living with disabilities reflects the fact that this group has historically been oppressed. “Women with disabilities have historically been marginalized and viewed as a socially ‘invisible population’...” (Ibid, p.177). This quote refers, as it states to the historical oppression of women living with disabilities, the greatest example of which could be the Eugenics Movement which occurred in the late 19th century and the first half of the 20th century (Dotson et al, 2003). However, while the Eugenics Movement is “over”⁴, women living with disabilities still suffer from extremely high levels of poverty, isolation, and abuse, and they continue to be excluded from “mainstream” society; this exclusion as Foster & Sandel (2010) argue is a form of systemic abuse. It is pertinent to note that all articles that took into account the impact of gender differences and how these affect women living with disabilities, maintain that this population experiences a double disadvantage since they face at least two forms of oppression simply by being women and by having a disability (i.e. sexism and ableism) (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Bumiller, 2008; Wells et al, 2012; Zitzelsberger, 2005; Long et al, 2011; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Sanders, 2007; Jeffreys, 2008). This “double disadvantage” leads women living with disabilities to be one of the most disenfranchised populations: over half of women living with disabilities in Canada live in poverty (Masuda, nd); women living with disabilities also have a higher unemployment rate than both men living with disabilities and women living without disabilities (Shandra & Chowdhury, 2012). For example, in the focus groups Masuda (nd) conducted with women living with disabilities in BC, she found that over 50 % of the participants were on welfare or welfare disability benefits. And within the interviews conducted by Tutty et al (2010b) with women

⁴ Although, theoretically, involuntary sterilization is no longer legal, birth control pills and Depo-Provera shots (a form of birth control), are often given to women living with disabilities with little to no explanation as to what these pills or shots are actually for. Thus, lack of informed consent in these cases is a real issue. Furthermore, surgical sterilization (presumably voluntary) is still often offered to adolescent girls and women living with disabilities as an option, more so than it is to those living without disabilities (Dotson et al, 2003).

living with disabilities who had experienced abuse, only 2 of the 10 women had jobs. Furthermore, research conducted by the DisAbled Women's Network in Canada has consistently shown that poverty and high unemployment rates continue to plague women living with disabilities in Canada (Masuda, nd; Riddell et al, 2003). Women living with disabilities also face higher rates of abuse than both men with disabilities and women living without disabilities (Richards et al, 2008) and yet are less likely to receive services to help with the abuse (Tutty et al, 2010a). For instance, in the interviews conducted by Tutty et al (2010a) of key individuals in community work with people living with disabilities in Canada, high rates of abuse among women living with disabilities were mentioned, as well as the many barriers to accessing services for this group. Women with disabilities also face greater barriers to accessing health: Masuda (nd) and Riddell et al (2003) both noted numerous barriers in their original research with women living with disabilities in BC such as lack of information, accessibility, stigma, and lack of supports. Women living with disabilities in Canada also have greater barriers to accessing housing or support services (Tutty et al, 2010a). For instance, in the research conducted by Tutty et al (2010b) with women living with disabilities in Calgary, many women in the study, mentioned lack of housing as a major stress in their lives. Not surprisingly, women living with disabilities also suffer from low self-esteem and self-worth, and are often extremely isolated (Ibid).

The articles composing this literature review especially made note of the marginalization women living with disabilities face in regard to their sexuality. Women with disabilities are often not considered to be "real" women (Riddell et al, 2003; Masuda, nd, Inahara, 2009; Zitzelsberger, 2005). In Zitzelseberger's (2005) qualitative study with 14 women living with disabilities, women talked about how their disability often altered the way people saw them or as Zitzelsberger (2005) argues "discourses of women with disabilities as nongendered, nonsexual, childlike and dependent extend to assumptions regarding women of being unable to be sexual, spouses, partners or mothers" (p. 395-396). These women talked about the hurt these assumptions and denial of sexuality caused them. This is unfortunately a theme which is repeated in other original research studies around the sexual health of women living with disabilities (Liddiard, 2014; Fritz et

al, 2015). Furthermore, these sexual stereotypes result in multiple sexual health inequities such as: less access to gynecological and breast health (Dotson et al, 2003; Masuda, nd; Riddell et al, 2003), higher risk of sexually transmitted infections (STIs) and sexually transmitted diseases (STDs) (Dotson et al, 2003), which includes a higher risk of HIV/AIDS (Wells et al, 2012), shame around masturbation and same-sex relationships, lack of information and knowledge about birth control and STIs/STDs (Dotson et al, 2003), fewer opportunities for romantic relationships or sexual expression, “greater barriers to communicating about sexuality” (p.526), barriers to family planning services (Shandra & Chowdhury, 2012), higher risk of abuse especially sexual violence (Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a), higher rates of “relationship breakdown” (Long et al, 2011, p.52) and finally, lower sexual self-esteem (Shandra & Chowdhury, 2012; Tutty et al, 2010a; Jeffreys, 2008; Zitzelsberger, 2005). Ultimately, all of these sexual health inequities are related to, compounded by, worsened, or contributed to by the main focus of this paper, namely, the lack of sexual health information, research, and services available to women living with disabilities, which is itself a systemic health inequity (Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Franco et al, 2012; Long et al, 2011).

Lack of Sexual Health Education, Information, Resources, Supports and Programs

The lack of sexual health information, education, or resources available for women living with disabilities is a health inequity, and this emerges as a strong theme in the literature (Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Franco et al, 2012; Long et al, 2011). Multiple authors mention the fact that women living with disabilities are excluded from “informal sex education”; what this means is that parents, caregivers, and peers often fail to talk about sexual health (Dotson et al, 2003; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al,

2010a). In other words, women living with disabilities are often excluded from discussions with peers and parents around sexual health and sexuality. This exclusion from informal sex education arises as a result of the stereotypes surrounding the sexuality of women living with disabilities as mentioned above (Dotson et al, 2003; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Franco et al, 2012). Unfortunately, this exclusion also carries over to health professionals; as Riddell et al (2003) found in their community action research with women living with disabilities in BC: Riddell et al (2003) argue that “many women with disabilities report that they receive health care only in the narrow area of their health that is directly impacted by their disability” (p.1). Furthermore, one of the main finds made by Franco et al (2012) in their analysis of 454 surveys completed by university students looking at attitudes towards the sexuality of people living with disabilities, is that health care professionals are not more evolved in their thinking towards women living with disabilities but alas are oftentimes less evolved in their thinking. What this means is that the health care system and its professionals continue to be influenced by negative stereotypes around the sexuality of women living with disabilities; this in turn negatively affects what services are available and how women living with disabilities are often treated in regards to their sexual health (Franco et al, 2012; Dotson et al, 2003; Richards et al, 2008; Masuda, nd; Riddell et al, 2003).

Regrettably, myths surrounding the sexuality of women living with disabilities continue to negatively affect their lives, and especially their sexual health (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Zitzelsberger, 2005; Tutty et al, 2010a; Tutty et al, 2010b; Richards et al, 2008). As Shandra and Chowdhury (2012) argue: women living with disabilities, “or their partners may internalize these stereotypes and feel less comfortable exploring their sexuality or engage in less positive sexual interactions. Thus, existing research suggests that peers, parents & a lack of social acceptance may all negatively affect the context...” (p.516). Unfortunately, this context results in a lack of sexual health information and resources for women living with disabilities, as noted by Long et al (2011) in their study of women living with disabilities in secure facilities, or by Dotson et

al (2003) in their study of the sexual knowledge of 8 women living with developmental disabilities, or by Masuda (nd) in their study on resources available to women living with disabilities in BC. Moreover, Shandra & Chowdhury (2012) also note that as a result of the stigma which surrounds the sexuality of women living with disabilities, this group often finds it harder to develop satisfying sexual relationships. Sadly, this dissatisfaction can often result in women living with disabilities to feel worse about themselves and their sexuality. As Shandra and Chowdhury (2012) state, there is a “critical need to provide sexual education that focuses not only on any specific impairments that may arise due to a young person’s disability but also on developing satisfying sexual relationships” (p.529).

In an evaluation of a computer-based interactive multimedia program by Wells et al (2012), they discovered that 76% of women living with disabilities who were part of the program (n= 25) said they didn’t use a condom the last time they had sex. Furthermore, in the assessment of a new screening tool to measure sexual health for women living with disabilities in secure facilities, Long et al (2011) found that “few answered questions correctly; many had potentially dangerous misconceptions; and there was a poor understanding of anatomy and physiology, sexual rights, sexuality and the law, and poor relationship skills” (p.52), and that “all showed a general lack of understanding about orgasm and foreplay” (p.55). Although this study dealt specifically with women living with disabilities residing in secure facilities (Long et al, 2011), and thus this issue may have been compounded by the situation, it still reflects the fact that for women living with disabilities “info is often not provided and there are limitations on what is actually discussed. Negative feelings in relation to sexuality often develop, resulting in low levels of sexual expression” (Richards et al, 2008, p. 189). This is unfortunate since “sex education is also pivotal to the development of positive self-image, interpersonal skills, and feelings of social competence in the area of sexuality” (Richards et al, 2008, p. 190).

Articles on Men Living with Disabilities

Notably, while there is an imbalance in the amount of articles in this critical literature review which look at disabilities in general, intellectual disabilities and physical disabilities, it is also important to remark that not all articles in this literature review looked specifically at women living with disabilities as their main focus. For instance, while all articles chosen for the review met the parameters of the search, and thus talked about women living with disabilities at some point; Richards et al (2008), Tutty et al (2010a), Tutty et al (2010b), Liddiard (2014), Wearing et al (2015), Breiding & Armour (2015), and Franco et al (2012), all had persons living with disabilities as their main focus. On the other hand, Sanders (2007), Jeffreys (2008), and Wilson and colleagues (2010) looked at men with disabilities as their central theme. Curiously, it is actually Jeffreys (2008) (whose main focus was on men living with disabilities) who emphasized the need to disaggregate current research surrounding disability and sexuality by gender differences. Furthermore, in the environmental literature scan done by Wilson et al (2010), they found that 26% of articles in the intellectual disability field did not mention gender differences; unfortunately, this study did not uncover what those statistics are for the disability field in general. Nonetheless, the lack of literature that solely looks at women living with disabilities gives credence to the argument that there is a lack of research about the sexual health of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011).

Yet, perhaps it is not quite apt to classify the articles of Jeffreys (2008) and Sanders (2007) as having men living with disabilities as their central focus; rather their main focus is on commercial sex and disability or as Jeffreys (2008) describes it in her title *Disability and the Male Sex Right*. On the other hand, I classified both articles as being mainly about men living with disabilities, since as both authors argue, the debate about having commercial sex become a right for people living with disabilities is actually a debate

attempting to justify the right for men living with disabilities to access commercial sex (Jeffreys, 2008; Sanders, 2007). As both authors note in their articles, even though the debate may be considered “gender neutral”, in actuality, it is not. It is the voices of men living with disabilities who are arguing for the right to commercial sex. This is not surprising since a majority of men living with disabilities currently use commercial or some form of facilitated sex, compared to a minority (if that) of women living with disabilities (Sanders, 2007; Jeffreys, 2008). Unfortunately, the voices of women living with disabilities are not considered in this debate, and both articles critique this sad state of affairs (Sanders, 2007; Jeffreys, 2008). Moreover, the differences between men living with disabilities and women living with disabilities are not considered. Women living with disabilities are considered doubly disadvantaged due to the fact that they face both sexism and ableism; women living with disabilities as a result experience greater marginalization than both men living with disabilities and women without disabilities (Sanders, 2007; Jeffreys, 2008). This marginalization is particularly striking when it comes to the sexual health of women living with disabilities since this population continues to suffer from sexist stereotypes which result in sexual health inequities (such as lack of sexual education) (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Zitzelsberger, 2005; Tutty et al, 2010a; Tutty et al, 2010b; Richards et al, 2008). Regrettably, the debate surrounding disability and commercial sex (similar to other discourses surrounding disability and sexuality) does not take into account how gender affects the context (Sanders, 2007; Jeffreys, 2008), thus giving weight to Jeffreys’ (2008) argument that current debates surrounding disability and sexuality need to disaggregate the context by gender.

Furthermore, Jeffreys (2008) goes further in her critique by contending that demanding the “male sex right” for men living with disabilities enables and promotes the continued sexual exploitation of women living with disabilities. It does this by promoting “an objectifying form of sexuality” (p.334) which is what women living with disabilities continue to suffer from. For instance, the argument surrounding disability and commercial sex for men living with disabilities implies that men have the right to sex (i.e. the “male sex

right”) without considering the voices of the women who are presumably meant to provide this service. The “male sex right” argument ends up objectifying and sexualizing women. It is from this objectification and sexualisation that many women living with disabilities suffer from, and it is from this, according to Jeffreys (2008), which stems their high rates of sexual violence and lack of sexual health education.

Contrarily, the third article which focuses primarily on men living with disabilities, by Wilson and colleagues (2010), critiques the disability literature (specifically the intellectual disability literature) for how it portrays men living with disabilities. Wilson et al (2010) conducted a thematic analysis of 4 primary intellectual disability journals by using the search terms “man”, “woman”, “men”, “women”, “male”, “female”, “girl”, and “boy” for the titles of all articles in these journals (p.1). They conducted this thematic analysis through a masculine perspective since the authors were concerned about the problematic depictions of men living with disabilities, and specifically of men living with intellectual disabilities, in the literature. They found 90 articles which met their search terms, of these “the most common theme for males was identified as ‘sexual matters’ (n=13), and for females it was ‘health and well-being’ (n=22). In contrast, there were fewer articles involving males whose theme was ‘health and well-being’ (n=10)...” (Wilson et al, 2010, p.3). This data justifies the authors argument that there seems to be a lack of research concerning “general health and well-being” for men living with intellectual disabilities in these 4 journals. On the other hand, the authors also found that “...there were fewer articles on ‘sexual matters’ for females (n=2)” (Wilson et al, 2010, p.3). Although this was not part of the authors’ main argument, this discrepancy is highly remarkable, and thus gives credence to the earlier argument that there is a lack of research available on the sexual health of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). It is also important to note that Wilson et al (2010) argue that the articles out there which do examine the sexual health of women and men living with disabilities, promote sexist stereotypes.

On the one hand, men living with disabilities are portrayed as pathologically sexually deviant, and women living with disabilities are portrayed as victims. This is not beneficial for either party, and is in fact extremely detrimental.

Abuse of Women Living with Disabilities

Woman being portrayed as victims is nothing new; this stereotype of women as “passive” and “without agency” continues to permeate society, and is often especially visible in the literature surrounding violence against women. This erroneous depiction continues to cause problems for women everywhere and it is especially problematic in its effects when it comes to women living with disabilities (Foster & Sandel, 2010). This is because women living with disabilities, as mentioned above, face at least two forms of oppression, and as a result already experience higher levels of marginalization (Inahara, 2009). As Foster & Sandel (2010) argue, when women living with disabilities are portrayed as “victims” this robs this already oppressed group of their agency. This does this population quite a disservice since women living with disabilities are incredibly strong and have the agency to fight this marginalization at both an individual and a group level (Foster & Sandel, 2010; Tutty et al, 2010b; Zitzelsberger, 2005). As Zitzelsberger (2005) claims in her qualitative study on the embodiment experiences of women living with disabilities, women living with disabilities continuously use their agentic power to navigate within a society that is rife with problematic stereotypes about women, disability and sexuality; sometimes they are also able to alter society’s unfavourable perceptions of them via exertion of this power and agency.

Furthermore, this stereotype of women living with disabilities as “victims” is emphatically evident in the literature surrounding violence against women living with disabilities (Wilson et al, 2010), which brings us to another section of this literature review. Namely, many of the articles comprised in this critical literature review either focused on (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b; Breiding & Armour, 2015) or commented on the abuse which many women living with disabilities

experience (Riddell et al, 2003; Richards et al, 2008; Jeffreys, 2008; Dotson et al, 2003). All authors who commented on this issue agree that women living with disabilities face unusually high rates of abuse (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b; Riddell et al, 2003; Richards et al, 2008; Jeffreys, 2008; Dotson et al, 2003). Women living with disabilities face higher rates of abuse than both men living with disabilities and women living without disabilities (Foster & Sandel, 2010). Women living with disabilities are also 3 to 4 times more likely to be sexually abused (Ibid). In a Canadian survey conducted by Yoshida et al (2011) of 1,095 women living with physical disabilities with the purpose of examining victimization data among Canadian women living with disabilities, it was found that “emotional abuse was reported by 57.4%, physical violence by 35.4 %, and sexual violence by 30.5 % of participants” (p.769). While this study gives an indication of the extent of abuse against women living with physical disabilities in Canada, it is still nonetheless, actually likely to be more extensive than this. Since this survey did not include women living in institutions where rates of abuse are known to be extremely high, combined with the fact that abuse itself is also known to be underreported, it is likely that rates of abuse are even higher in Canada than suggested by this survey (Yoshida et al, 2011). Furthermore, this survey only looked at women living with physical disabilities, and thus gives no indication of the rates of women living with other forms of disability; however, the reports by Tutty et al (2010a; 2010b) done in Canada suggest that rates of abuse among women living with disabilities in general, are similarly high.

All authors who brought up the issue of violence against women living with disabilities agree that these uncommonly high rates of abuse among women living with disabilities are caused by the double disadvantage which this group faces due to the intersection of ableism and sexism (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b; Riddell et al, 2003; Richards et al, 2008; Jeffreys, 2008; Dotson et al, 2003). Going back to the Canadian survey of 1.095 women living with disabilities mentioned above, Yoshida et al (2011) found after analyzing their data that “Those who reported cultural identities other than Canadian (OR = 1.93, 95% CI = 1.12–3.32) were more likely to have reported

experiencing physical and/or sexual violence, as were those with an annual household income less than \$20,000 (OR = 3.21, 95% CI = 1.97–5.25) or between \$20,000 and \$49,999 (OR = 2.08, 95% CI = 1.29–3.36). Women with two or more health conditions (OR = 3.2, 95% CI = 1.93–5.32) and those who had some or most activities limited by pain were also more likely to report having experienced physical and/or sexual violence (OR=1.61, 95% CI=1.08–2.41)” (p.762). Thus, Yoshida and colleagues (2011) argue that violence against women living with disabilities intersects with other forms of oppression (besides that of ableism and sexism) to increase rates of violence. For instance, not only do ableist notions of ability and sexist notions of femininity combine to increase women living with disabilities’ vulnerability to violence; but this vulnerability can be further compounded when it intersects with poverty or racism or others forms of oppression, as reflected by the higher rates of physical and sexual violence experienced by these populations in Yoshida et al (2011) original research. These findings found by Yoshida et al (2011) are very intersectional in nature and reflect how truly complex this issue is, they also help lend weight to my argument that the use of intersectionality theory in analyzing this issue is necessary.

Exclusion from Sexual Health Arena as Abuse

Another illuminating argument found in the literature is the argument that the lack of sexual health information and resources available to women living with disabilities is itself a form of abuse (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011). Richards et al (2008) believe that sexual abuse also “includes denial of sexuality, denial of sexual education and information...” (p.187). Or as Foster & Sandel (2010) put it “Such institutional barriers can, in and of themselves, be viewed as indirect forms of abuse.” (p.181). Basically, the argument here is that the lack of sexual health information, resources, or education directed towards women living with disabilities is in and of itself a form of abuse. Whether the authors believe that this exclusion constitutes a form of sexual abuse as Richards et al (2008) do, or a form of systemic abuse as do Tutty et al (2010a), is unimportant in the

face of the fact that these authors agree that this societal exclusion from sexual health resources is abuse, regardless of what type they may categorize it as (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011). I personally find this finding significant since as mentioned above and as proven in this paper there is a lack of research surrounding the sexual health of women living with disabilities; given the lack of sources I was able to find on this subject, that 5 of these sources (more than 18% of my findings) agree that the omission of women living with disabilities from sexual health information, resources, education, and research, quantifies as abuse reflects my argument that this exclusion is itself a systemic health inequity (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011).

While the exclusion of women living with disabilities from the sexual health discourse in general is incredibly problematic, and as noted above, can be seen as a form of abuse and as a systemic health inequity; it unfortunately also exacerbates the problem at hand. The authors argue that lack of sexual health resources for women living with disabilities increases their risk for experiencing abuse, while at the same time experiencing abuse increases their need for sexual health resources (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011). Since women living with disabilities already experience incredibly high rates of abuse (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b; Riddell et al, 2003; Richards et al, 2008; Jeffreys, 2008; Dotson et al, 2003), and suffer from a lack of sexual health resources, information, and education (Dotson et al, 2003; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b; Long et al, 2011), it is very sobering to realize that the interplay between these two elements creates a vicious cycle where one worsens the other ad nauseum. For example, lack of sexual health information and education itself is harmful since it can lead to some women living with disabilities being unable to navigate this sphere of life, and thus increases the likelihood of them being unable to recognize or circumvent abusive behaviour. However, lack of representation also leads to negative effects such as lack of self-esteem, low confidence, and isolation; this

is problematic especially in a group who has been shown to already suffer from low feelings of self-worth. Furthermore, lack of self-worth and isolation are also risk factors in being unable to recognize or circumvent abusive behaviour (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011). Moreover, exclusion at a societal or systemic level marginalizes the group in question and this leads to very real health effects such as higher rates of abuse and lack of access to health care; how this group is perceived societally impacts how they are treated by others, as well as impacting which resources they are able to access (Tutty et al, 2010a). In essence, what these authors are arguing is that the systemic exclusion of women living with disabilities from the sexual health arena contributes to the social inequities in health this group already faces, and may also be a contributing factor to these inequities in the first place (Foster & Sandel, 2010; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Yoshida et al, 2011).

Intersections of Sexism and Disability

In the next few paragraphs I want to put special emphasis on the interplay of intersections of privilege and oppression which I came across during this literature review. As a health inequity, the lack of sexual health information, resources, and education which women living with disabilities face, is already intersectional in nature by the very fact that we are looking at how sexism and ableism interact to cause this systemic health inequity (Foster & Sandel, 2010). However, regardless of the fact that this inequity in and of itself is already intersectional, it is still important to analyze how differences play out in the lived experiences of women living with disabilities in regards to their lack of sexual health resources, since whether they are at an intersection or not, this group is not a homogenous group, and the experiences of women living with disabilities will vary from individual to individual (Foster & Sandel, 2010; Tutty et al, 2010b; Zitzelsberger, 2005).

Interestingly, there were a few intersectional findings which were quite surprising and somewhat counterintuitive. For example, in the survey conducted by Yoshida et al (2011) with 1,095 women living

with disabilities in Canada, they found that for women living with disabilities “that those who were more educated, less mobile, more socially isolated, and those who had higher levels of depression were more likely to have experienced abuse in the past year” (p.764). Whereas Jeffreys (2008) found that for women living with disabilities there is a higher risk for sexual violence when they are “young and non-white women, unmarried women and employed women” (p.329). Within both these statements of compiled statistics, there are some unexpected and counterintuitive findings - namely that women living with disabilities who are more educated are at higher risk for abuse (Yoshida et al, 2011), and women living with disabilities who are employed are at higher risk for sexual violence (Jeffreys, 2008). In both these cases, it seems like a site of privilege (i.e. employment and education) leads to higher risk for marginalization. Neither article conjectures why that is (Jeffreys, 2008; Yoshida et al, 2011) but intersectionality theory can be very useful in pulling apart the mechanisms that could lead to these types of counterintuitive consequences (Hankivsky & Christoffersen, 2008). Additionally, these findings both showcase that sites of oppression and privilege are not always multiplicative and can sometimes interact and compound in unknown ways (Ibid).

An interesting intersectional fact which arose in my critical review of the literature, is how age affects the lack of sexual resources women living with disabilities are able to access. Two of the articles in the review deal explicitly with how the sexuality or sexual health of adolescent girls living with disabilities is impacted by the dearth of research, info, and resources (Klett & Turan, 2012; Shandra & Chowdhury, 2012). Unfortunately, none of the articles in the review deal with the other side of the coin - notably, how this experience changes for older women living with disabilities as it pertains to their sexual health. This seems to be a significant gap in an area of research which is already incredibly under-researched (Yoshida et al, 2011; Tutty et al, 2010a; Tutty et al, 2010b), and may indicate that older women living with disabilities might be further marginalized when it comes to sexual health research, education, resources, and information, than women living with disabilities in general. However, it is also possible that older women living with disabilities are not further marginalized but may be protected in some way by their social

location. Notably, in their analyses of victimization data among 1,095 Canadian women living with disabilities, Yoshida et al (2011) found that older women living with disabilities had lower rates of violence. However, without further research, it is hard to know how age or being an older woman affects the sexual health of women living with disabilities.

Regardless of this gap, the articles by Klett & Turan (2012), and Shandra and Chowdhury (2012), provide a valuable addition to the field by exploring how the lack of representation in general for women living with disabilities in the sexual health arena, plays out when it comes to adolescent girls living with disabilities. The article by Klett & Turan (2012) *Generalized Effects of Social Stories with Task Analysis for Teaching Menstrual Care to Three Young Girls with Autism* is very specific in its focus. As the title indicates this article is focusing primarily on young adolescent girls with autism; it is also looking at the effects of a particular program which aims to increase skills related to menstrual care. While this article's focus is very narrow, it still provides an interesting look at how adolescent girls living with disabilities' (in this case autism) sexual health is impacted, or more specifically how their sexual health skills and what they are taught can be impacted by their disability. By showing the beneficial effects of a social stories program aimed towards girls with autism, the authors argue that programs aimed toward adolescent girls living with disabilities (or women living with disabilities) make a difference and help rectify this sexual and systemic health inequity (Klett & Turan, 2012).

The article by Shandra & Chowdhury (2012) *The First Sexual Experiences among Adolescent Girls with and without Disabilities* is very important because it takes a sample of girls (N=2,729) (ages 12-24) from the National Longitudinal Survey of Youth to examine how disability status affects female adolescent sexuality. Considering the dearth of research in this area (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011), it is really exciting to see an article taking such an

intersectional approach to the subject matter. As Shandra & Chowdhury state about their study “Findings indicate that disability status is important to consider when examining adolescent sexuality: however, not all youth with disabilities have equal experiences” (p.515). This quote is relevant for many reasons. First of all, unsurprisingly it provides evidence that disability status affects experiences and perceptions of adolescent sexuality. However, the second part of the quote is also a good reflection of why intersectionality itself as a theory is necessary; just because a group of people may belong to a certain marginalized community, does not mean all their experiences will be the same. This is why an approach such as intersectionality, which aims to tease out these differences, is important in understanding how something like disability status can function and impact differently on multiple levels (Hankivsky & Christoffersen, 2008).

Unsurprisingly, Shandra & Chowdhury (2012) note that there is lack of research (as did Klett & Turan [2012]) on how disability status affects sexuality for adolescent girls living with disabilities. However, Shandra & Chowdhury’s (2012) research helps rectify this gap by providing interesting insight on this issue, namely, that disability status affects adolescent girls’ experience of sexuality in many ways. First, adolescent girls living with disabilities are shown to internalize negative stereotypes surrounding women with disabilities. For instance, young girls and women living with disabilities have lower sexual self-esteem than their peers, and many see their disability as a significant barrier to developing romantic relationships. These negative stereotypes also can result in social isolation for adolescent girls living with disabilities since many of the peers of these girls and often these girls’ partners have also internalized these negative depictions of young women with disabilities, and thus buy in, and sometimes help propagate harmful stereotypes about women living with disabilities. Young women with disabilities are also sexually excluded systemically by the fact that there is a lack of sexual health information or resources available to them. While this general lack can create social exclusion and negative internalization of stereotypes, the fact that there is a lack of disability-specific sexual information can also create anxiety and an inability for certain adolescent girls with disabilities to navigate their sexuality (Shandra & Chowdhury, 2012). Furthermore,

Shandra & Chowdhury (2012) found that parents (similar to peers, and even partners) may also treat adolescent girls living with disabilities differently when it comes to their sexuality, and as a result may create more barriers for these young women to have healthy romantic relationships and a healthy sense of sexuality. Shandra & Chowdhury (2012) also place this issue within the larger context by pointing out that unhealthy romantic relationships and a negative sense of sexuality also have very real health effects.

The article by Long et al (2011), *Assessing the Sexual Knowledge of Women in Secure Settings: The Development of a New Screening Measure*, is also very interesting from an intersectional point of view, since as the title indicates, this article is examining the sexual knowledge of women living in secure settings via an original research study which piloted the use of a new screening measure to quantify the sexual knowledge of women living with disabilities in secure settings. Most, if not all, women living in secure settings have a disability. Living in secure settings also usually indicates a certain heightened level of severity for the disability in question and thus often women who live in these situations have the most severe forms of disabilities. As a result, some of the oppression, marginalization, and effects of this type of stigma may be heightened in this group compared to women living with disabilities who do not live in secure settings (Long et al, 2011). As Long et al (2011) state “Little research has been published on the need for sexual education for women in secure psychiatric facilities” (p.51). As the article also argues, women living in secure settings have poor sexual health knowledge, which is extremely dangerous since they are more vulnerable and more at risk for abuse, unwanted pregnancies, STIs and HIV to name a few. For example, the pilot study found that when women living in secure settings were asked questions about sexual knowledge “few answered questions correctly; many had potentially dangerous misconceptions; and there was a poor understanding of anatomy and physiology, sexual rights, sexuality and the law, and poor relationship skills” (Long et al, 2011, p.52). This is especially troubling since this group (even more so than women living with disabilities in general who already have disturbingly high rates of abuse) is also at high risk for abuse and sexual coercion; if they were provided with adequate sexual education, instead of being

excluded at every turn, this could help in lowering their vulnerability to abuse and sexual coercion (Long et al, 2011).

Long et al's (2011) findings about how societal exclusion plays into lack of sexual knowledge for women living with disabilities in secure settings, and how this may contribute to their high rates of abuse helps lead into other points of intersection involving abuse and women living with disabilities which were found during this critical literature review. Unsurprisingly, as mentioned above, in their survey of victimization data from 1,095 surveys of Canadian women living with disabilities, Yoshida et al (2011) found that while women living with disabilities are already extremely likely to experience violence, this vulnerability increases when it intersects with other forms of oppression. For example, both racism (i.e. being a woman of colour) and poverty increase the likelihood of experiencing violence. As argued previously, women living with disabilities already face at least two forms of oppression (ableism and sexism) which intersect to create heightened vulnerability to certain negative health outcomes such as the fact that women living with disabilities are already 3 to 4 times more likely to experience sexual violence (Foster & Sandel, 2010). It is unsurprising then, (yet still incredibly unjust and awful), that this compounding of two forms of marginalization (sexism and ableism) and its increased likelihood of negative health and life effects is further compounded by other forms of oppression (Yoshida et al, 2011).

This increased vulnerability also holds true for women with multiple disabilities or more severe forms of disability (i.e. more limiting in their daily life) (Tutty et al, 2010a; Yoshida et al, 2011). As Tutty et al (2010a) state "Women with multiple disabilities indicated being victims to several forms of abuse' (p.16-17). Notably, this increased likelihood to experience health inequities for women living with disabilities who have more severe forms of disability, two or more health conditions, are women of colour, etc., holds true for more than a heightened risk of violence. For instance, Jeffreys (2008) argues "Women with developmental disabilities and the most severe forms of disability, were less likely to be partnered though research suggests that they receive a particularly severe degree of violence" (p.329). Or as Dotson et al

(2003) maintain “Women with more severe disabilities are routinely absent from sexual research studies due to a lack of appropriate tools and research designs. Unfortunately, these might be the women whose needs and experiences are least understood and most requiring of attention through research” (p.208). This aggravation of negative health effects for women with severe disabilities or other women living with disabilities who also experience a third form of marginalization, is disturbing. As we know from this critical literature review that while many women living with disabilities already face numerous health and life consequences as a result of sexism and ableism, they are also often the most ignored societally in terms of resources, support, recognition, awareness, and health services (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). Unsettlingly, this trend seems to hold true within the population of women living with disabilities as a whole as well, i.e. within this “group” of people (women living with disabilities), those who face additional forms of oppression (such as severity, racism, etc.) also tend to get the most severe consequences while being the most ignored (Dotson et al, 2003; Jeffreys, 2008; Tutty et al, 2010a; Yoshida et al, 2011).

Another interesting argument that arises in the research conducted by both Yoshida et al (2011) and Tutty et al (2010b) with Canadian women living with disabilities is the link between disability and abuse. As is well known, abuse can lead to negative health outcomes; in turn these health outcomes can become disabilities. Moreover, as argued by Jeffreys (2008), women living with disabilities who experience violence have a higher likelihood of experiencing negative health outcomes from those experiences than women living without disabilities who also experience violence. For instance they are more likely to have “negative health outcomes including injury, chronic pain, depression, PTSD, substance abuse, homicide, and suicide” (p.329). However, as shown in the literature, there is also a strong link between disability and increased likelihood of experiencing violence (Foster & Sandel, 2010; Yoshida et al, 2011; Tutty et al, 2010a; Tutty et

al, 2010b; Riddell et al, 2003; Richards et al, 2008; Jeffreys, 2008; Dotson et al, 2003); this creates a horrible feedback loop where disability can lead to abuse, and abuse can lead to disability and vice versa. In this type of negative interrelationship, where an experience of marginalization (abuse) can feed into further marginalization (disability and ableism) and vice versa (i.e. disability leads to abuse), it is important to examine why they are so closely linked. If such a feedback loop exists, one must question why? Furthermore, such a close link between disability and abuse (which often has sexual health connotations or negative outcomes) lends further support to the idea that many women living with disabilities in Canada experience vast sexual health inequities, including their lack of access to education, information, supports and resources (Yoshida et al, 2011; Tutty et al, 2010b).

Another gap which was found during this critical literature review was the lack of research on women living with hidden disabilities⁵. For the purpose of this review, hidden disabilities simply refer to disabilities which are generally not visibly evident. Although, sometimes certain authors exclude physical disabilities (i.e. disabilities generally having to do with mobility and often considered to have to do with the senses and/or limbs) and hidden disabilities (Tutty et al, 2010a; Tutty et al, 2010b), I feel this is an erroneous distinction which creates an untrue and arbitrary binary where visible=physical and hidden=mental/intellectual and may in fact worsen stigma around hidden disabilities as being “less valid” than physical disabilities (Tutty et al, 2010a; Tutty et al, 2010b). Furthermore, this binary is erroneous since many “hidden” disabilities can be physical (i.e. I identify as having a “hidden” physical disability).

Hidden disabilities are only briefly touched upon in two articles of this critical literature review (Tutty et al 2010a; Tutty et al, 2010b). Similar to women with more severe disabilities or multiple disabilities (Dotson et al, 2003; Jeffreys, 2008; Tutty et al, 2010a; Yoshida et al, 2011), young women (Klett & Turan, 2012; Shandra & Chowdhury, 2012), older women living with disabilities, women of color, or women living

⁵ This area is of special importance to me personally (i.e. please see Positionality section) and thus may have affected why I noticed/was drawn to this gap.

in poverty (Yoshida et al, 2011), this subgroup of women (i.e. women living with hidden disabilities) seems to be largely ignored in the research which is problematic since as has been well established earlier in this critical literature review, there is a lack of research on the health concerns or (really just concerns) of women living with disabilities (Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). Not surprisingly, Tutty et al (2010a) argue that women living “with hidden disabilities are further misunderstood or ignored...” (p. 2). Whereas, Tutty et al (2010b) found during their interviews with women living with disabilities in Alberta, that for some women living with hidden disabilities “the invisibility of their condition resulted in being denied help, support and understanding” (p.44). This for me, is an especially important point or argument⁶, while having a hidden disability definitely comes with the privilege of not having to disclose and also the privilege of being perceived as and often treated as “able-bodied”; the flipside to this privilege is that somehow your disability is perceived as “less valid” or “less real”, and as Tutty et al (2010b) contend, can result in “being denied help, support and understanding” (p.44).

The next couple of points, found using an intersectional viewpoint during this review, are not entirely cohesive although of course they are all intersectional, and often deal with minorities within a minority (i.e. women living with disabilities). They were just findings of note that I felt should be included in an intersectional critical literature review surrounding the systemic lack of sexual health research and resources for women living with disabilities. Masuda (nd) states in their study with BC women living with disabilities: “First Nations women with disabilities spoke of discrimination as one of the big factors in not feeling healthy” (p.19). This was the only mention of Aboriginal women (although it only refers to First Nations women) found in the entire review and another huge gap in the literature with another subgroup completely ignored (Masuda, nd). Richards et al (2008) also make note that when it comes to LGBTQIA and women living with disabilities, they are a “minority within a minority” (p.195) and are of course another subgroup ignored in the literature (Richards et al, 2008). Richards et al (2008) also point out earlier in their

⁶ I have my own personal experiences dealing with this (i.e. please see Positionality section).

article that up to 80% of people living with intellectual disabilities lose their children. This finding is also supported by Braswell (2015) who also notes that disproportionate levels of children are taken away from mothers living with disabilities. However, since their article, *Sexual and Human Rights of People with Intellectual Disabilities*, did not take a gendered approach (Richards et al, 2008), and since the article by Braswell (2015) is mostly based on his experiential knowledge of being taken away from his mother who has a disability, and since we have established that women living with disabilities often face double the marginalization (Inahara, 2009), it would be noteworthy to take a closer look at how this reality can play out for women living with disabilities who have children, and how this could impact their sexual health (Richards et al, 2008).

Recommendations

Research:

Finally to summarize the critical review of the literature, I will talk about the recommendations laid out by the authors of the articles in this review. Later in this paper I will have my own section where I lay out my own recommendations (informed, of course, by the literature); however, in this section I will focus on what recommendations the articles in the review laid out. Although many authors agree there is a lack of research on the sexual health of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011), only a certain amount mention it specifically as a recommendation i.e. Dotson et al, 2003; Jeffreys, 2008; Sanders, 2007; Shandra & Chowdhury, 2012; and Tutty et al, 2010b. However, considering the general consensus among the authors on the lack of research, this seems to be one of the prevalent recommendations discovered in the literature review (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007;

Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). Dotson et al (2003) and Zitzelsberger (2005) go further in this recommendation by arguing that the voices of the women themselves (i.e. women living with disabilities) should be represented in the literature as well. As Dotson et al (2003) argue, the voices of women living with disabilities regarding their own sexuality are “largely absent from the literature” (p.196). This is horrendous and nonsensical; it is important that women living with disabilities are able to maintain ownership over their own sense of sexuality, and this extends to research looking into this issue (Dotson et al, 2003). Jeffreys (2008) also argues for the need for more research into this area to focus specifically on the needs of women living with disabilities since as mentioned previously much of the research focuses simply on people living with disabilities (i.e. like many of the articles in this review) and does not disaggregate the interests of women and men living with disabilities. This of course is erroneous since the reality is very different for women living with disabilities than it is for men living with disabilities due to the intersection of ableism and sexism. Thus, Jeffreys (2008) maintains that research in this area needs to take a feminist approach.

Information and “Self-Responsibility”:

Several authors recommend that information about health services for women living with disabilities be more readily available and accessible (Foster & Sandel, 2010; Jeffreys, 2008; Long et al, 2011; Masuda, nd; Riddell et al, 2003; Tutty et al, 2010a; Yoshida et al, 2011) and also that there should be more information regarding the sexuality of women living with disabilities in general (Foster & Sandel, 2010; Jeffreys, 2008; Long et al, 2011; Masuda, nd; Riddell et al, 2003; Tutty et al, 2010a; Yoshida et al, 2011). A few authors made mention specifically of the fact that women living with disabilities not knowing the health services available to them was a very big barrier to their sexual health (Riddell et al, 2003; Masuda, nd). In both research studies conducted in BC on barriers to health, women living with disabilities identified lack of

information as a barrier to their health (Riddell et al, 2003; Masuda, nd) Furthermore, the notion of “self-responsibility” (Riddell et al, 2003, p.22) on the parts of the women living with disabilities themselves arose as a recommendation (Masuda, nd; Richards et al, 2008; Riddell et al, 2003). “Self-responsibility” refers to the fact that women living with disabilities wish to advocate for themselves (at least according to the research conducted by Masuda [nd] and Riddell et al [2003]); they want to be recognized for their own agentic power, and the services and supports they recommend implementing are those that would empower women living with disabilities to accomplish this. While it is incredibly important to recognize that women living with disabilities have agency and indeed want supports and programs that enable them to gain more agency, it is also important not to put the sole responsibility of an ableist and sexist system on them. For instance, it is not fair to put the sole responsibility of “fixing” the system on those who are often most oppressed by it; although at the same time it is also incredibly important not to devalue or underestimate the power and agency women living with disabilities do have to alter inequities and obviously, information and supports that enable them to do this are very valuable indeed (Masuda, nd; Richards et al, 2008; Riddell et al, 2003).

Increased Representation in Sexual Health Services and Programs:

Dotson et al (2003) and Wells et al (2012) also explicitly mention and argue that the lack of representation women living with disabilities experience in regards to their sexuality is itself harmful, and both authors recommend that this be rectified. Moreover, Wells et al (2012) argue that women living with disabilities are excluded from health promotion programs in general and this exclusion helps cause the various health inequities they experience, and that this exclusion is especially true when it comes to sexual health programs. Another common recommendation that arose in this critical literature review is the recommendation for more sex education for women living with disabilities; specifically, sex education which is targeted towards women living with disabilities (Richards et al, 2008; Shandra & Chowdhury, 2012; Tutty

et al, 2010a, Yoshida et al, 2011). While sex education may exist in most schools, often young women living with disabilities are excluded from informal sex education from peers or parents, or the general curriculum itself, thus sex education tailored towards women living with disabilities which takes into account the marginalization they face in this area is greatly needed (Shandra & Chowdhury, 2012). In this same vein, many authors believe that it is important that more sexual health programs and resources for women living with disabilities be implemented (Dotson et al, 2003; Long et al, 2011; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012). This is a population which receives very few supports and high levels of marginalization, especially when it comes to their sexuality, thus, programs and resources which help rectify this are very needed (Dotson et al, 2003; Long et al, 2011; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012). Zitzelsberger (2005) further argues that it is important that women living with disabilities are exposed to alternative discourses such as feminism and deaf culture, which will enable them to take a more politically active role, since Zitzelsberger (2005) maintains that the perceptions of women living with disabilities themselves are very important and have the power to alter the perceptions of others. In fact Zitzelsberger found in her qualitative study on the embodiment of the lived experiences of women living with disabilities, that once a woman living with a disability is able to recognize the ableism and sexism that impact her, with her own agency she is sometimes able to positively alter perceptions of how others view her, and women living with disabilities in general (Ibid).

Funding and Policy:

Interestingly, some of the articles also mention the issue of funding, and maintain that in Canada especially, cuts to funding, and the funding climate in general, has affected the lack of supports, resources, programs, and information for women living with disabilities (Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011). In Tutty et al's (2010a) environmental scan of programs that address the needs of people living

with disabilities, and in their needs assessment conducted with key informants in the community, funding came up as a big issue in both these cases. They argue that funding is necessary to improve the sexual health inequities that women living with disabilities in Canada are experiencing. Tutty et al (2010a) also mention the fact that the funding is often temporary, which makes it hard to establish programs or health prevention programs that will actually be effective. Thus, Tutty et al (2010a) recommend that funding be permanent in order to create effective programs and services. Tutty et al (2010a) also mention that there need to be policy shifts in Canada since the policies themselves are often harmful to women living with disabilities. Services for the sexual health of women living with disabilities in Canada are incredibly sparse and the ones that do exist are very fragmented (Ibid). Moreover, as mentioned previously, Dotson et al (2003) strongly espouse for the inclusion of the voices of women living with disabilities, and this recommendation extends to programs and policies which might impact this group. They believe that women living with disabilities need to have input in all policies or programs which would affect them (Ibid).

Discussion

Summary of Critical Review

This critical literature review has shown that many women living with disabilities experience undue marginalization, especially when it comes to their sexual health (Inahara, 2009; Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Bumiller, 2008; Wells et al, 2012; Zitzelsberger, 2005; Long et al, 2011; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Sanders, 2007; Jeffreys, 2008). Research regarding the sexuality of women living with disabilities is sparse (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). This group is often also excluded from sex education (Richards et al, 2008; Shandra & Chowdhury, 2012; Tutty et al, 2010a, Yoshida et al, 2011) and there is also a lack of sexual health programs, supports, resources (Dotson et al, 2003; Long et al, 2011; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012), and information for women living with disabilities (Foster & Sandel, 2010; Jeffreys, 2008; Long et al, 2011; Masuda, nd; Riddell et al, 2003; Tutty et al, 2010a; Yoshida et al, 2011); this exclusion constitutes a systemic health inequity. Furthermore, the marginalization and exclusion women living with disabilities face is often exacerbated for women in this group who experience a third form of marginalization, such as severity of disability (Dotson et al, 2003; Jeffreys, 2008; Tutty et al, 2010a; Yoshida et al, 2011), women of colour (Yoshida et al, 2011), women with “hidden” disabilities (Tutty et al, 2010a; Tutty et al, 2010b), women who identify as LGBTQIA (Richards et al, 2008), and women in poverty (Yoshida et al, 2011).

Limitations

Some of the main limitations of this critical literature review are the articles which comprise this review itself. As mentioned previously, it was very hard to find articles that specifically dealt with the

sexuality of women living with disabilities themselves. Thus, much of the findings of this review are gleaned from articles which while they provide some analysis of the sexuality of women living with disabilities; it is not their main focus. For instance, the articles by Richards et al (2008), Tutty et al (2010a), Tutty et al (2010b), Liddiard (2014), Wearing et al (2015), Breiding & Armour (2015) and Franco et al (2012), are articles which look at the experiences of people living with disabilities as a whole. Furthermore, a few of the articles look specifically at men living with disabilities (Sanders, 2007; Jeffreys, 2008; Wilson et al, 2010). While this review is looking at women living with disabilities in general, some of the articles only focus on certain types of disabilities. Whereas a couple of the articles look only at Autism (Klett & Turan, 2012; Bumiller, 2008) and many of the articles look at developmental disabilities specifically (Dotson et al, 2003; Franco et al, 2012; Long et al, 2011; Richards et al, 2008; Wells et al, 2012; Bernert & Ogletree, 2013), only a few look at physical disabilities (Inahara, 2009; Yoshida et al, 2011; Zitzelsberger, 2005). One article looks at women living with rheumatoid arthritis (Areskoug-Josefsson & Oberg, 2009) while another looks at spinal cord injury only (Fritz et al, 2015). However, a further limitation of this paper may have been that I would have garnered more results if I had searched by disability type or specific disabilities, rather than using the term “disability” as a catch all search term. Finally, one of the articles looks specifically at the circumstances of women living in secure facilities which may also skew the findings since it is known that marginalization rates may be exacerbated in secure facilities (Long et al, 2011).

Implications for public health practice and/or policy

The implications of this critical literature review for women living with disabilities in Canada are quite clear: women living with disabilities experience high rates of marginalization (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Zitzelsberger, 2005) especially when it comes to their sexual health and violence (Foster & Sandel, 2010; Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011), and yet are often excluded from the system (Jeffreys, 2008; Richards et al,

2008; Tutty et al, 2010a; Yoshida et al, 2011). There is a lack of research regarding the sexuality of women living with disabilities (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011), as well as a lack of programs, resources, supports, and information(Dotson et al, 2003; Masuda, nd; Riddell et al, 2003; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011).This marginalization and exclusion constitutes a systemic sexual health inequity and unfortunately this systemic sexual health inequity is often exacerbated for women in this group who experience a third form of oppression (Dotson et al, 2003; Jeffreys, 2008; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011).

Disability and Intersectionality Theory

Moodley & Graham (2015), Pal (2011), and Shaw, Chan & McMahon (2012) all argue for the use of intersectionality theory in deconstructing disability. As Pal (2011) puts it “The critical issue is that the interface of disability with other social identities is more likely to compound problems, which by and large are overlooked” (p.154). All authors of these three articles argue that intersectionality theory is necessary when analyzing disability because of the inherent complexity of how disability interacts with other social locations (Moodley & Graham, 2015; Pal , 2011; Shaw, Chan & McMahon, 2012). Moodley & Graham (2015) specifically talk about how it is important to use intersectionality theory when it comes to women living with disabilities, since it is necessary to examine how disability and gender intersect (as well as other social locations) to form specific health outcomes for women living with disabilities. Pal (2011) argues that “special consideration needs to be given to such sections who languish behind because of the interplay of more than one social location” (p.175). Whereas Shaw et al (2012) warn that not using intersectionality theory to deconstruct disability and other intersecting categories can have “disastrous”(p.84) consequences for those who fall at these intersections. Finally, all these authors argue that it is imperative to use

intersectionality theory to analyze disability and all other intersecting social locations (Moodley & Graham, 2015; Pal , 2011; Shaw, Chan & McMahon, 2012).

Recommendations

As mentioned previously in the Framework section of this paper, I will now be using some of the guiding principles of intersectionality theory (intersecting categories, multi-level analysis, and diverse knowledge's') to guide my recommendations.

Intersecting Categories

I agree with many of the recommendations laid out in the literature comprising this critical literature review. Namely, similar to many authors in the critical literature review, I believe it is important further research be done regarding the sexuality of women living with disabilities (Dotson et al, 2003; Jeffreys, 2008; Sanders, 2007; Shandra & Chowdhury, 2012; and Tutty et al, 2010b). I also agree with Jeffreys (2008) that this research should be feminist and disaggregated since, as Jeffreys (2008) argues, the needs and experiences of women living with disabilities are different than those of men living with disabilities or women living without disabilities. Disaggregated research done by gender is also imperative due to the lack of research in Canada on the sexual health of women living with disabilities (Masuda, nd; Yoshida et al, 2011). And as one might guess from the previous section "Disability and Intersectionality Theory", I also believe it is important that future research in this area be done using an Intersectionality Theory approach and lens (Moodley & Graham, 2015; Pal, 2011; Shaw et al, 2012). As Pal (2011) argues:

"There are persons with disabilities who experience multiple disadvantages because of interplay of more than one social identity. Understanding the problems of these groups has a powerful human rights dimension in respect to proper advocacy, plan of action, adequate support for the equitable development and designing of a universal framework of inclusiveness" (p.160).

Research using intersectionality theory needs to be done on the sexual health outcomes of women living with disabilities in general since, as established, there is a lack of research in this area (Foster & Sandel,

2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011). Similar to recommendations by Yoshida et al (2011) who had the beginnings of intersectional research started in their findings that women living with disabilities in Canada who live in poverty, are women of colour, or have multiple disabilities, experience higher levels of physical and sexual violence, I also believe that further intersectional research should be done on other intersecting categories. What I mean by this is while women living with disabilities are an intersecting category themselves, there are women within this group who face at least a third form of oppression who are a “minority within a minority” (p.195) who face even higher levels of oppression than the already exacerbated levels which many women living with disabilities already face, and yet are even more “invisible” (Richards et al, 2008). For example, the intersecting categories of women living with disabilities: who have more severe disabilities or multiple disabilities (Dotson et al, 2003; Jeffreys, 2008; Tutty et al, 2010a; Yoshida et al, 2011), young women (Klett & Turan, 2012; Shandra & Chowdhury, 2012), older women living with disabilities, women of color, or women living in poverty (Yoshida et al, 2011), Aboriginal women (Masuda, nd), women who identify as LGBTQIA (Richards et al, 2008), moms living with disabilities (Braswell, 2015), women living with “hidden” disabilities (Tutty et al, 2010a; Tutty et al, 2010b), and women living in secure settings (Long et al, 2011). Many of these intersecting categories face exacerbated outcomes, and yet are largely absent and “invisible” from the literature. In a population, which has historically and continues to be, hidden from view and made invisible (Foster & Sandel, 2010) this seems incredibly problematic and needs to be rectified. Intersectionality theory research would be a very useful tool to analyze how the interactions between these intersecting categories compound, and create unique health outcomes for these groups (Moodley & Graham, 2015; Pal, 2011; Shaw, Chan & McMahon, 2012).

Multi-Level Analysis

I believe that a multi-level analysis of this issue is necessary since many of the needed changes (i.e. recommendations informed by the literature) fall at various levels. For instance, similar to many authors, I agree that programs, resources, and supports for women living with disabilities need to be established (Dotson et al, 2003; Long et al, 2011; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012) and that sex education (Richards et al, 2008; Shandra & Chowdhury, 2012; Tutty et al, 2010a; Yoshida et al, 2011) and information regarding health services be tailored towards this group (Foster & Sandel, 2010; Jeffreys, 2008; Long et al, 2011; Masuda, nd; Riddell et al, 2003; Tutty et al, 2010a; Yoshida et al, 2011). Similar to Dotson et al (2003) and Tutty et al (2010a), I also take an upstream approach and believe there should be policy shifts which would enable the creation of supports for women living with disabilities. It is also important (especially in the Canadian context) that permanent funding for resources and programs for women living with disabilities be established (Tutty et al, 2010a; Tutty et al, 2010b; Yoshida et al, 2011). I also agree that the lack of representation for women living with disabilities in all sexual health programs and arenas is itself an issue which needs to be rectified (Dotson et al, 2003; Wells et al, 2012). While I agree with many of the various recommendations laid out in the literature to create programs or sex education or have more support or information, similar to Dotson et al (2003), it is the mass effect, the systemic inequity, of this exclusion at various levels which deeply troubles me. It is this systemic exclusion which needs to be rectified.

A multi-level analysis of the “macro (global and national-level institutions and policies), meso or intermediate (provincial and regional-level institutions and policies) and micro levels (community-level, grassroots institutions and policies as well as the individual or ‘self’)”, would be very useful, in order to best enact many of the recommendations laid out above, as well as to provide an analysis of which recommendations (and at what levels) are best suited to combat this systemic exclusion (Hankivsky et al, 2012, p.35). For example, at which level should policies be enacted that would be most helpful in

combatting systemic sexual health inequities - provincial or national? Should sex education for women living with disabilities be done at the micro (i.e. community level) or provincial level? A multi-level analysis could help answer some of these questions, and provide us with some insight in how to best remedy this systemic exclusion. Contrarily, it appears that since I am arguing that this exclusion is a systemic issue, it would be best if recommendations were done at the macro level. However, I feel this is an erroneous assumption, since it is very possible that due to the agentic power which women living with disabilities hold as a community, as highlighted by many of the experiences of women living with disabilities laid out in original research in the literature, that implementations at an individual or community level might be more effective (Zitzelsberger, 2005; Masuda, nd; Riddell et al, 2003; Dotson et al ,2003). Thus, a multi-level analysis could help pinpoint how to best implement these recommendations in order to mend the systemic health inequity of the exclusion of women living with disabilities from the sexual health arena (Hankivsky et al, 2012).

Diverse Knowledge's'

As Hankivsky et al (2012) argue "Including the perspectives and worldviews of people who are typically marginalized or excluded in the production of knowledge can work towards disrupting forces of power" (p.37). The knowledge which women living with disabilities hold is a form of "diverse knowledge's" and one that needs to be included in order to disrupt the systems of power (namely sexism and ableism among others) which currently marginalizes them. I agree with Dotson et al (2003) that it is imperative that the voices of women living with disabilities themselves be included at all levels i.e. research, programs, policies, etc. It is essential that they are able to have some degree of ownership over the programs, policies, and services that affect them. Thus, one of my key recommendations is that women living with disabilities' voices need to be included in any future research, sexual health programs, services, or supports, sexual education, sexual health information, and policies (Dotson et al, 2003).

Conclusion

In conclusion, women living with disabilities in Canada are experiencing a systemic sexual health inequity due to the fact they are excluded from research and sex education, lack supports, programs, information, and resources (Foster & Sandel, 2010; Riddell et al, 2003; Masuda, nd; Dotson et al, 2003; Yoshida et al, 2011; Sanders, 2007; Klett & Turan, 2012; Shandra & Chowdhury, 2012; Richards et al, 2008; Tutty et al, 2010a; Tutty et al, 2010b; Wells et al, 2012; Jeffreys, 2008; Zitzelsberger, 2005; Long et al, 2011). This systemic sexual health inequity will only be rectified when intersectional research (including a multi-level analysis) has been done on the sexual health needs of women living with disabilities and which includes the voices of women that are themselves living with disabilities. This research can then lead to the development of intersectional sexual health programs, information, sex education, supports, and resources for women living with disabilities in Canada which reflects their own needs and inputs, and which aims to rectify this systemic sexual health inequity.

References

- Areskoug-Josefsson, K., & Oberg, U. (2009). A literature review of the sexual health of women with rheumatoid arthritis. *Musculoskeletal Care*, 7(4), 219-226 8p. doi:10.1002/msc.152
- Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, 57(3), 240-249 10p. doi:10.1111/j.1365-2788.2011.01529.x
- Braswell, H. (2015). My two moms: Disability, queer kinship, and the maternal subject. *Hypatia*, 30(1), 234-250. doi:http://dx.doi.org.proxy.lib.sfu.ca/10.1111/hypa.12125
- Breiding, M. J., & Armour, B. S. (2015). The association between disability and intimate partner violence in the United States. *Annals of Epidemiology*, 25(6), 455-457 3p. doi:10.1016/j.annepidem.2015.03.017
- Bumiller, K. (2008). Quirky citizens: Autism, gender, and reimagining disability. *Signs*, 33(4), 967-991. Retrieved from <http://search.proquest.com.proxy.lib.sfu.ca/docview/61667979?accountid=13800>
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum* 1989, 139-168.
- Dotson, L. A., Stinson, J., & Christian, L. (2003). "People tell me I can't have sex": Women with disabilities share their personal perspectives on health care, sexuality, and reproductive rights. *Women & Therapy*, 26(3), 195-209. Retrieved from <http://search.ebscohost.com.proxy.lib.sfu.ca/login.aspx?direct=true&db=c8h&AN=2005099275&site=ehost-live>

- Foster, K., & Sandel, M. (2010). Abuse of women with disabilities: Toward an empowerment perspective. *Sexuality and Disability, 28*(3), 177-186.
doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1007/s11195-010-9156-6>
- Franco, D. G., Cardoso, J., & Neto, I. (2012). Attitudes towards affectivity and sexuality of people with intellectual disability. *Sexuality and Disability, 30*(3), 261-287.
doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1007/s11195-012-9260-x>
- Fritz, H. A., Dillaway, H., & Lysack, C. L. (2015). "Don't think paralysis takes away your womanhood": Sexual intimacy after spinal cord injury. *American Journal of Occupational Therapy, 69*(2), 1-10 10p.
doi:10.5014/ajot.2015.015040
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal, 26*(2), 91-108. doi:10.1111/j.1471-1842.2009.00848.x
- Hankivsky, O., & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Journal of Critical Public Health, 18*(3), 271-283.
- Hankivsky, O., Grace, D., Hunting, G., Ferlatte, O., Clark, N., Fridkin, A., Giesbrecht, M., Rudrum, S., & Laviolette, T. (2012). An Intersectionality-Based Policy Analysis Framework. Retrieved from <http://www.sfu.ca/iirp/ibpa.html>
- Inahara, M. (2009). This body which is not one: The body, femininity and disability. *Body & Society, 15*(1), 47-62. doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1177/1357034X08100146>

Jeffreys, S. (2008). Disability and the male sex right. *Women's Studies International Forum*, 31(5), 327-335.

doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1016/j.wsif.2008.08.001>

Kehmann, K. (2005). The provision of sexual health care for adult women with learning disabilities. *Journal of Community Nursing*, 19(9), 10-14 3p. Retrieved from

<http://proxy.lib.sfu.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=106548634&site=ehost-live>

Klett, L. S., & Turan, Y. (2012). Generalized effects of social stories with task analysis for teaching menstrual care to three young girls with autism. *Sexuality and Disability*, 30(3), 319-336.

doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1007/s11195-011-9244-2>

Liddiard, K. (2014). The work of disabled identities in intimate relationships. *Disability & Society*, 29(1), 115-128. doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1080/09687599.2013.776486>

Long, C., G., Krawczyk, K., M., & Kenworthy, N., E. (2013). Assessing the sexual knowledge of women in secure settings: The development of a new screening measure. *British Journal of Learning Disabilities*, 41(1), 51-65. doi:10.1111/j.1468-3156.2011.00722.x

Masuda, S. (nd). *Women with disabilities: We know what we need to be healthy!* Vancouver, BC, Canada: British Columbia Centre of Excellence for Women's Health.

Moodley, J., & Graham, L. (2015). The importance of intersectionality in disability and gender studies. *Agenda*, 29(2), 24. doi:10.1080/10130950.2015.1041802

Pal, G. C. (2011). Disability, intersectionality and deprivation. *Psychology and Developing Societies*, 23(2), 159-176. doi:10.1177/097133361102300202

- Richards, D., Miodrag, N., Watson, S. L., Feldman, M., Aunos, M., Cox-Lindenbaum, D., & Griffiths, D. (2008). Sexuality and Human Rights of Persons with Intellectual Disabilities. In Owen F., Griffiths D. (Eds.), *Challenges to the human rights of people with intellectual disabilities* (p.184-218). London, GBR: Jessica Kingsley Publishers.
- Riddell, L., Greenberg, K., & Meister, J. (2003). *We're women, too: Identifying barriers to gynecologic and breast health care for women with disabilities*. (). Vancouver, BC, Canada: British Columbia Centre of Excellence for Women's Health.
- Sanders, T. (2007). The politics of sexual citizenship: Commercial sex and disability. *Disability & Society*, 22(5), 439-455. doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1080/09687590701427479>
- Shandra, C. L., & Chowdhury, A. R. (2012). The first sexual experience among adolescent girls with and without disabilities. *Journal of Youth and Adolescence*, 41(4), 515-532.
doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1007/s10964-011-9668-0>
- Shaw, L. R., Chan, F., & McMahon, B. T. (2012). Intersectionality and disability harassment: The interactive effects of disability, race, age, and gender. *Rehabilitation Counseling Bulletin*, 55(2), 82-91.
doi:10.1177/0034355211431167
- Tutty, L. M., Giurciu, B., & Moorey, K. (2010). *No longer silent: Persons with disabilities who have been abused identify their service needs*. (). Calgary, AB, CAN: RESOLVE, University of Calgary.
- Tutty, L. M., Moorey, K., & LeDrew, S. A. (2010). *Persons with disabilities and abuse across the lifespan: Environmental program scan and community stakeholder needs assessment*. (). Calgary, AB, CAN: RESOLVE, University of Calgary.

Wearing, S., Gunaratnam, Y., & Gedalof, I. (2015). Frailty and debility. *Feminist Review*, (111), 1-9.

doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1057/fr.2015.39>

Wells, J., Clark, K., D., & Sarno, K. (2012). A computer-based interactive multimedia program to reduce

HIV transmission for women with intellectual disability. *Journal of Intellectual Disability*

Research, 56(4), 371-381. doi:10.1111/j.1365-2788.2011.01482.x

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., Shuttleworth, R. P., & Parker, D. (2010). A masculine

perspective of gendered topics in the research literature on males and females with intellectual

disability. *Journal of Intellectual & Developmental Disability*, 35(1), 1-8.

doi:10.3109/13668250903496351

Yoshida, K., DuMont, J., Odette, F., & Lysy, D. (2011). Factors associated with physical and sexual

violence among Canadian women living with physical disabilities. *Health Care for Women*

International, 32(8), 762-775. doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1080/07399332.2011.555826>

Zitzelsberger, H. (2005). (In)visibility: Accounts of embodiment of women with physical disabilities and

differences. *Disability & Society*, 20(4), 389-403.

doi:<http://dx.doi.org.proxy.lib.sfu.ca/10.1080/09687590500086492>

Appendix A

	Original Research	Reports, Reviews, Analyses, and Perspectives
Areskoug-Josefsson & Oberg, 2009		✓
Bernert & Ogletree, 2013	✓	
Braswell, 2015		✓
Breiding & Armour, 2015	✓	
Bumiller, 2008		✓
Dotson et al, 2003	✓	
Foster & Sandel, 2010		✓
Franco et al, 2012	✓	
Fritz et al, 2015	✓	
Inahara, 2009		✓
Jeffreys, 2008		✓
Klett & Turan, 2012	✓	
Lehmann, 2005		✓
Liddiard, 2014	✓	
Long et al, 2011	✓	
Masuda, nd	✓	
Richards et al, 2008		✓
Riddell et al, 2003	✓	
Sanders, 2007		✓
Shandra & Chowdhury, 2012	✓	
Tutty et al, 2010a	✓	
Tutty et al, 2010b	✓	
Wearing et al, 2015		✓

Wells et al, 2012	✓	
Wilson et al, 2010	✓	
Yoshida et al, 2011	✓	
Zitzelsberger, 2005	✓	

Appendix B

	Canada	United States	United Kingdom	Australia	Sweden	Portugal
Areskoug-Josefsson & Oberg, 2009					✓	
Bernert & Ogletree, 2013		✓				
Braswell, 2015			✓			
Breiding & Armour, 2015		✓				
Bumiller, 2008	✓					
Dotson et al, 2003	✓					
Foster & Sandel, 2010	✓					
Franco et al, 2012						✓
Fritz et al, 2015		✓				
Inahara, 2009	✓					
Jeffreys, 2008				✓		
Klett & Turan, 2012		✓				
Lehmann, 2005			✓			
Liddiard, 2014			✓			
Long et al, 2011			✓			
Masuda, nd	✓					
Richards et al, 2008	✓					
Riddell et al, 2003	✓					
Sanders, 2007			✓			
Shandra & Chowdhury, 2012		✓				
Tutty et al, 2010a	✓					

Tutty et al, 2010b	✓					
Wearing et al, 2015			✓			
Wells et al, 2012		✓				
Wilson et al, 2010				✓		
Yoshida et al, 2011	✓					
Zitzelsberger, 2005	✓					